

# ANNUAL REPORT

FISCAL YEAR

# 16

Includes special feature  
on NCBDDD's Zika virus response



**National Center on Birth Defects  
and Developmental Disabilities**







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Coleen A. Boyle, PhD, MS (Hyg)  
Director

## Message from the Director

It takes a great team to build a great organization. As I review the details of this report, it is clear the accomplishments recounted within it are the result of extraordinary collaboration by the Center's most important asset—its people. At every layer of our organization, each individual plays a valued part in moving the National Center on Birth Defects and Developmental Disabilities (NCBDDD) forward.

During the past year, we have collectively embarked on a journey to advance our vision and ensure babies are born healthy, children reach their potential, and everyone thrives. Even with constant exposure to change, NCBDDD and our partners remained enthusiastic about the contributions to our vision.

This report documents a year's accomplishments and forward progress toward our vision in what has been a highly critical year for NCBDDD. A year we remember for many reasons and one that saw NCBDDD do something it has never done before—be at the forefront of a public health emergency response: CDC's emergency response to Zika virus. The spread of Zika virus necessitated a global effort from public health, clinicians, laboratorians, and mosquito control experts. At the center of this effort, dedicated people from NCBDDD worked long hours—days, nights, weekends, and holidays—from our headquarters and traveling to other nations to render assistance and unraveling mysteries of the virus to help protect babies and pregnant women.

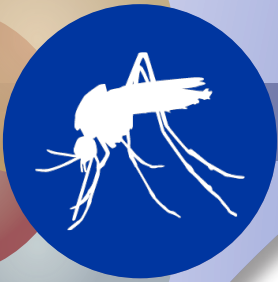
It is with these unprecedented challenges in mind that I am distinctly pleased to present this year's annual report of scientific achievements and accomplishments, including a special feature on NCBDDD's ongoing response to the Zika virus crisis. As you will see, this publication assembles a truly remarkable compilation of insights, advances, and discoveries across our Center's topics shaped by our equally remarkable and dedicated staff.

Our Vision

*Babies*  
are born healthy.  
*Children*  
reach their potential.  
*And everyone*  
thrives.

NCBDDD is an organization of action; a community of engaged professionals who create, pursue, perform, and achieve in support of the Center's mission and vision. In this report, you will see a snapshot of that activity and the remarkable opportunities that NCBDDD embarked upon, which taken together, make for an incredibly powerful and inspiring Center story of commitment and success.

NCBDDD staff are making a difference and as we approach 2017, I look forward to tackling the deep needs that remain.



## NCBDDD Zika Virus Response

Public health professionals frequently investigate new disease-causing germs and respond to emergencies. But an investigation in January 2016 began differently, and NCBDDD staff soon found themselves in a situation not seen in modern times. Zika virus, which previously caused pretty mild disease, was found to be causing more serious consequences, particularly, birth defects.

### The Beginning

Scientists discovered Zika virus and its mild symptoms decades ago. In the years since, there were two small outbreaks of the virus in humans, but none as widespread as the 2015/2016 outbreak in the Americas. In late 2015, troubling reports began to appear from Brazil; increased numbers of birth defects of the brain and cases of Guillain-Barré syndrome were occurring in regions with Zika outbreaks. Was Zika causing these severe health outcomes? Was there something else causing this increase in birth defects?

*Public health professionals frequently investigate new disease-causing germs and respond to emergencies. But an investigation in January 2016 began differently, and NCBDDD staff soon found themselves in a situation not seen in modern times.*

NCBDDD staff consulted with colleagues in the United States and outbreak countries to better understand this mystery. On January 22, 2016, CDC activated its Emergency Operations Center (EOC). The goal of the emergency response was simple: protect mothers and their babies by increasing awareness of Zika and helping individuals and communities understand what they could do to decrease the chance of Zika virus exposure. However, the journey to get to that goal has been full of challenges.

### Solving a Mystery

Staff from NCBDDD and other Centers in CDC worked day and night to answer the question: “Is there a link between Zika virus and birth defects?” Pieces of evidence began to form a more complete picture. On April 13, 2016, CDC published a synthesis of the evidence concluding that Zika virus infection during pregnancy is a cause of microcephaly (small head and brain) and other severe fetal brain defects.

On any given day, several hundred CDC staff were assigned to the emergency response; many remained at the Atlanta headquarters, while dozens deployed to states, US territories, and other countries. NCBDDD staff worked numerous strategies throughout the emergency response, including sharing information with the public, learning more about how the Zika virus affected people, and establishing partnerships with groups beneficial to the mission.







# NCBDDD Zika Virus Response

## Protecting Women and Babies

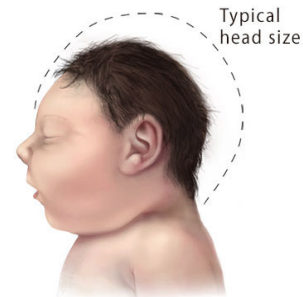
Many of the NCBDDD volunteers were assigned to the newly formed EOC Pregnancy and Birth Defects Task Force. Its mission was to reduce the risk and the effect of Zika virus infection in pregnant women, infants, and children. Task Force personnel achieved this goal through numerous efforts, including:

- Conducting populations monitoring and research to collect critical information about Zika virus infection in pregnancy.
- Educating the public, health professionals, communities, public health agencies, and government officials about Zika prevention.
- Conducting research to understand Zika virus infection in pregnancy.
- Providing clinical consultations to healthcare providers caring for pregnant women and technical assistance to public health officials.
- Providing technical assistance, both in the United States and internationally.
- Understanding how to prevent Zika virus infection and how best to communicate that information.
- Preventing Zika-related birth defects by preventing unintended pregnancy.
- Engaging and sharing information with partner organizations, such as the March of Dimes, the American Academy of Pediatrics, American College of Obstetricians and Gynecologists, and Association of Maternal and Child Health Programs.

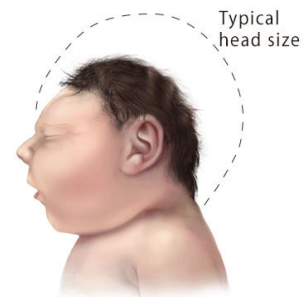
Graphic showing the effects of Microcephaly, one of the results of the Zika virus.



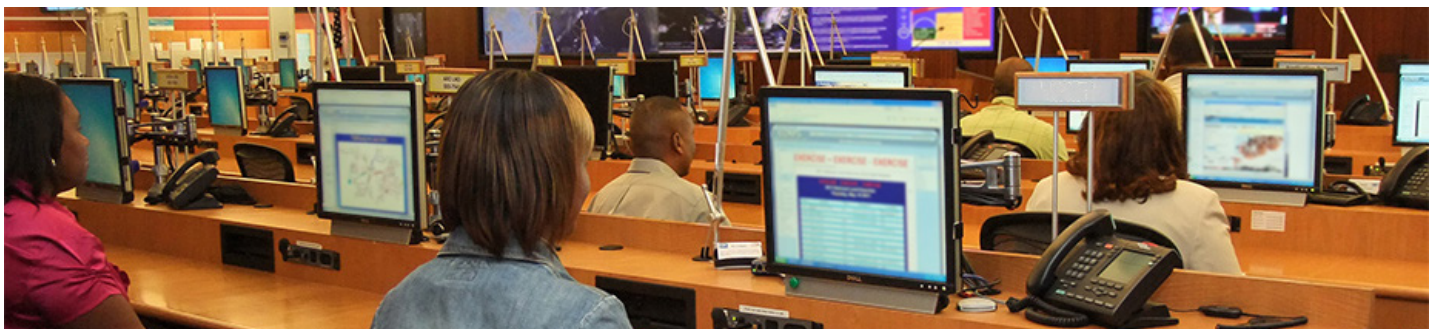
Baby with Typical Head Size



Baby with Microcephaly



Baby with Severe Microcephaly



Emergency Operations Centers: CDC Emergency Operations Center (EOC)

# NCBDDD Zika Virus Response

## Understanding Zika's Impact on Babies

Although Zika is not new, its potential effects on pregnancy are a new phenomenon. CDC leaders and scientists quickly recognized the critical need for information and established the infrastructure to collect data to guide public health action. To monitor the effect of Zika virus infection during pregnancy, pregnancy and infant surveillance was put in place domestically and internationally:

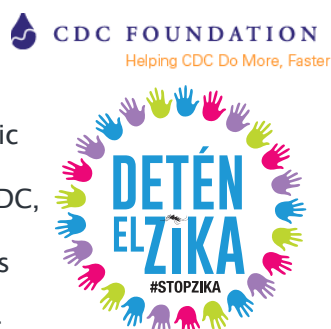
- the U.S. Zika Pregnancy Registry (USZPR),
- the Puerto Rico Zika Active Pregnancy Surveillance System, and
- Proyecto VEZ in Colombia.

The information collected through these systems were rapidly translated into messages for the general public and updated clinical guidance.

The systems provided critical data to answer key questions. For example, data reported to the USZPR from the continental United States and Hawaii suggested that among pregnant women with laboratory evidence of possible Zika virus infection anytime during the pregnancy, about 6% of fetuses and infants had a birth defect potentially related to Zika virus. Of those with a Zika infection specifically in the first trimester, about 11% had a birth defect potentially related to Zika virus.

## Crucial Partnerships

Other NCBDDD staff developed and enhanced partnerships with organizations outside of public health. The CDC Foundation (CDCF) worked closely with CDC, focusing its partnership and fundraising efforts on projects for women and their sexual partners in high-risk areas for Zika, including Puerto Rico. Early in the emergency response, CDCF worked with donors to provide products for Zika Prevention Kits to protect pregnant women. Benefactors to CDCF provided several substantial donations, including contributions of condoms, bed nets, and mosquito control tablets, and other partnerships were successful in providing women



and their sexual partners in Puerto Rico with improved access to a range of contraceptive methods.

In early summer, with generous private sector funding support, staff from NCBDDD, CDCF, and contractors developed and implemented a multifaceted communication campaign called "This is How We Stop Zika" or "Deten el Zika". This campaign was aimed at educating pregnant women and communities in U.S. territories about Zika prevention. The highly successful campaign was conducted in Puerto Rico from June to October 2016.

## The Consequences of Zika

Through the efforts of NCBDDD scientists, health educators, and communicators, along with others from CDC and public health agencies in the United States and abroad, more information is being discovered daily about Zika virus and its effects on pregnant women, infants, children, and others. As CDC Director Dr. Tom Frieden said, "We need a robust response to protect American women and reduce to the greatest extent humanly possible the number of families affected. We don't know who those children will be. We don't know where they will grow up. But anything we don't do now, we will regret not having done later."

## Preparing For the Next Threat

Birth defect surveillance systems provide crucial information about emerging health threats and their effects on babies. They are essential for connecting affected families to services they need and to ensure that babies are born healthy, children reach their potential, and everyone thrives. At the beginning of 2016, CDC supported 14 states to track birth defects. CDC's commitment to fight Zika has enabled us to make a significant effort to accomplish activities to strengthen infrastructure for the future.

Before another Zika epidemic hits, CDC and its partners must build on this infrastructure and birth defects expertise to rapidly identify, understand, and prevent emerging threats so every baby in every city, state, and territory is protected. We must better understand the effects of exposures during pregnancy; prevent exposures where possible; and improve care for babies, children, and adults who are living with birth defects.



## SAVING BABIES

Through Birth Defects Prevention and Research

*CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is working toward a day when all babies are born with the best health possible.*



Birth defects are common, costly, and critical. Every 4 ½ minutes, a baby is born with a major birth defect in the United States. Babies born with a birth defect are more likely to die before their first birthday compared to babies born without a birth defect. Babies who survive and live with birth defects can have lifelong challenges.

NCBDDD's state-based birth defects tracking and public health research provide a wealth of information used to identify causes of birth defects, find opportunities to prevent them, and improve the health of those living with birth defects.

### Accomplishments

- Interviewed more than 1,400 mothers of newborns with and without birth defects for the Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS). Results from BD-STEPS will provide more knowledge about the factors that might increase or decrease the risk of having a baby with a birth defect.
- Continued our work in the United States to prevent neural tube defects—serious birth defects of the brain and spine—by providing scientific assistance to the Corn Masa Flour Working Group on their successful petition to the U.S. Food and Drug Administration (FDA). This FDA approval allows for the addition of folic acid to corn masa flour and other corn-based products, such as corn tortilla chips, which can help prevent neural tube defects. Through our Birth Defects COUNT global initiative, we provided expert input to our partners in India, the country with the highest burden of neural tube defects, which led to revised standards for fortifying foods with appropriate amounts of folic acid so as to prevent many neural tube defects.
- Expanded research and delivered reliable information about safer medication use in pregnancy through Treating for Two. Presented



# SAVING BABIES

## Through Birth Defects Prevention and Research

new information on the frequency of filling prescriptions for antidepressants among women of reproductive age.

- Provided new data and research on fetal alcohol spectrum disorders (FASDs), including a report on alcohol use during pregnancy, which estimated more than 3 million U.S. women are at risk for an alcohol-exposed pregnancy. Provided guidance for healthcare clinicians on the identification, diagnosis, and care for children and teens with behavioral problems associated with prenatal alcohol exposure. Partnered with the Administration for Children and Families and initiated project to identify children within the child welfare system who were exposed to alcohol before birth, thereby improving their care.
- Presented updated estimates on the number of people living in the United States with congenital heart defects (CHDs), which helps policymakers and healthcare systems plan to meet the health needs of the growing population of adults with CHDs.

## Looking to the Future

Our ongoing state-based birth defects tracking system and public health research continue to form the scientific foundation for preventing birth defects and helping people thrive throughout their lives. Our research helps us to better understand the causes of birth defects and the lifelong cost and quality of life issues that affect those with birth defects and their families. Together, with our partners, we continue to work toward the day when all babies are born with the best possible health.

In the U.S. each year, the total **costs for hospital care** of children with birth defects exceed



## Notable 2016 Scientific Publications

Dasgupta S, et al. Patterns in Zika virus testing and infection, by report of symptoms and pregnancy status — United States, January 3–March 5, 2016. *MMWR Morb Mortal Wkly Rep*. 2016 Apr 22;65(15):395-399.

Dawson AL, et al. Twinning and major birth defects, National Birth Defects Prevention Study, 1997-2007. *J Epidemiol Community Health*. 2016 Nov;70(11):1114-21.

Dawson AL, et al. Antidepressant prescription claims among reproductive-aged women with private employer-sponsored insurance - United States 2008-2013. *MMWR Morb Mortal Wkly Rep*. 2016 Jan 29;65(3):41-6.

Gilboa SM, et al. Congenital heart defects in the United States: Estimating the magnitude of the affected population in 2010. *Circulation*. 2016 Jul 12;134(2):101-9.

Green PP, et al. Vital signs: Alcohol-exposed pregnancies — United States, 2011–2013. *MMWR Morb Mortal Wkly Rep*. 2016 Feb 5;65(4):91-7.

Grosse SD, et al. Retrospective assessment of cost savings from prevention: Folic acid fortification and spina bifida in the U.S. *Am J Prev Med*. 2016 May;50(5Suppl 1):S74-S80.

Hagan JF, et al. Neurobehavioral disorder associated with prenatal alcohol exposure. *Pediatrics*. 2016 Sep 27;138(4):e20151553.

Orozco AM, et al. Characteristics of US adults aged ≥ 19 years with a usual daily folic acid intake above the tolerable upper intake level: National Health and Nutrition Examination Survey 2003-2010. *Nutrients*. 2016 8(4):195.

Razzaghi H, et al. Impact of missing data for body mass index in an epidemiologic study. *Matern Child Health J*. 2016 Jul;20(7):1497-505.

Yeung LF, et al. Ascertaining the burden of birth defects. *Am J Prev Med*. 2016 May;50(5):672-3.

Zaganjor I, et al. Describing the prevalence of neural tube defects worldwide: A systematic literature review. *PLoS One*. 2016 Apr 11;11(4):e0151586.



## SAVING BABIES

### Through Birth Defects Prevention and Research

#### **Spotlight On:** **MotherToBaby**

This spotlight was contributed by Christina Chambers, PhD, MPH, MotherToBaby epidemiologist

MotherToBaby, a service of the nonprofit Organization of Teratology Information Specialists, provides free, evidence-based information to the public and healthcare providers online and by telephone about medications and other exposures during pregnancy and breastfeeding. “You have given me so much insight, truth, and hope about being pregnant and being a mom,” stated R.M., an expecting mom from Georgia who contacted MotherToBaby. Truth about birth defects is what MotherToBaby strives for and hope for new prevention methods is what it often achieves.

This work is critical. Birth defects affect 1 in 33 infants. A key component of the National Center on Birth Defects and Developmental Disabilities’ (NCBDDD’s) mission includes birth defects prevention. MotherToBaby has worked closely with NCBDDD on efforts affecting the public. For example, in 2005, MotherToBaby partnered with NCBDDD to provide fact sheets on exposures, such as infections, medications, and chemicals, affecting pregnant women during Hurricane Katrina. In 2009-2010, MotherToBaby worked with NCBDDD to develop a preparedness plan for pregnant women in advance of the pandemic H1N1 influenza outbreak. In 2016, MotherToBaby partnered with NCBDDD to provide expert consultation to concerned women regarding the Zika virus disease.

For more than 15 years, MotherToBaby has contributed information on the safety of medications and vaccines during pregnancy by conducting critical observational research studies. In 2016, we had ongoing studies on asthma, autoimmune and immune-mediated conditions (such as rheumatoid arthritis, psoriasis, Crohn disease and ulcerative colitis, and multiple sclerosis), seasonal flu vaccine, and the pertussis vaccine. These much needed studies allow women and healthcare providers to make informed decisions to prevent or reduce the risk of birth defects while simultaneously trying to keep the mom healthy.



## HELPING CHILDREN

Live to the Fullest by Understanding  
Developmental Disabilities

*CDC's National Center on Birth Defects  
and Developmental Disabilities (NCBDDD) is  
committed to learning more about developmental  
disabilities in order to help children and their  
families get the support they need.*

Developmental disabilities, such as attention-deficit/hyperactivity disorder (ADHD), autism, cerebral palsy, hearing loss, and vision impairment, are some of the most significant child health issues facing families and our nation today. About 1 in 6 children in the United States have developmental disabilities or other developmental delays.

NCBDDD is studying how common developmental disabilities are, identifying factors that can put children at risk, exploring possible causes, and improving identification of developmental delays so children and families can get the services and support they need as early as possible.

### Accomplishments

- Published a new analysis from the Autism and Developmental Disabilities Monitoring (ADDM) Network on the prevalence and characteristics of autism spectrum disorder (ASD) among 8-year-old children. The investigation found that about 1 in 68 of these children were identified with ASD, based on tracking in 11 communities in the United States. An early ADDM study of 4-year-old children found that progress had been made in identifying children with ASD at younger ages. Information from ADDM can help promote early identification of children with ASD, plan for service needs of children with ASD and their families, guide research, and inform policy.
- Implemented the third phase of the Study to Explore Early Development (SEED). During the next 5 years, CDC will invest more than \$27 million to carry out SEED 3. SEED is the largest study in the United States to help identify factors that may put children at risk for ASD. SEED 3 is enrolling 2,500 children at risk for ASD, which will increase total SEED enrollment to 7,500 children. CDC will also fund a site to conduct a brief follow-up study of children enrolled





## HELPING CHILDREN

### Live to the Fullest by Understanding Developmental Disabilities

in the first phase of SEED, who will now be teenagers. The goal of this follow-up study is to better understand the long-term health and development of children identified as having autism at younger ages.

- Trained and supported 45 Act Early Ambassadors in 41 states and three territories. These ambassadors promote developmental monitoring and screening to help young children with developmental delays be identified and connected with appropriate services and support as early as possible. This collaboration with the ambassadors and other partners resulted in the integration of Learn the Signs. Act Early. materials into a number of programs that serve young children, such as pediatricians' offices, Women, Infants, and Children (WIC) clinics, Head Start centers, and childcare and home visiting programs. These efforts resulted in a monthly average of more than 155,000 unique visitors to the Learn the Signs. Act Early. website, as well as 45,000 downloads of materials and more than 178,000 hard copy materials requested each month.
- Presented a CDC *Vital Signs* article to increase awareness and knowledge of behavior therapy as the recommended first-line treatment for young children with ADHD. The published Vital Signs article in *Morbidity and Mortality Weekly Report*, and supporting materials, such as the Finding a Therapist Fact Sheet, sparked more than 1,000 news articles. Related webinars also increased knowledge about effective behavior therapy for ADHD in young children among more than 2,300 clinicians and parents to date via collaborations with partners.
- Continued leading the national effort to collect quality data on babies and young children who are deaf and hard of hearing (D/HH). Quality data is defined as complete, timely,

and accurate, and can help state and territorial programs ensure that all babies who are D/HH are identified early and receive intervention services that help them reach their full potential. NCBDDD supports efforts to standardize the accurate collection, analysis, and reporting of Early Hearing and Detection Intervention (EHDI) data ensuring it is comparable between states and territories. The latest data collected by CDC shows that more than 6,000 infants in the United States with a permanent hearing loss were identified early.

### Looking to the Future

NCBDDD and its partners have been working for more than 15 years to track, research, and provide useful tools and information on developmental

disabilities. Identifying developmental concerns at the earliest possible age offers children the best chance at early intervention and treatment. As we learn more about developmental disabilities, we ensure that children can live to their fullest potential. For ADHD, that means assuring that best practices are currently used for treatment. For ASD, it means giving communities the information that will best serve the needs of children and families. Through Learn the Signs. Act Early we will continue to develop high quality, effective tools to empower parents, health professionals, and communities to closely monitor development and act early on developmental concerns. For EHDI, we focus on helping states and territories have the data systems they need to ensure all deaf and hard of hearing children are identified early and can receive intervention services to help them reach their full potential.

Medical costs for children with autism are estimated to be



**SIX TIMES HIGHER**  
than for children without autism



# HELPING CHILDREN

## Live to the Fullest by Understanding Developmental Disabilities

### Notable 2016 Scientific Publications

Bitsko RH, et al. Health-care, family, and community factors associated with mental, behavioral, and developmental disorders in early childhood – United States, 2011-2012. *MMWR Morb Mortal Wkly Rep*. 2016 Mar 11;65(9):221-6.

Christensen DL, et al. Prevalence and characteristics of autism spectrum disorder among children aged 8 years – Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2012. *MMWR Surveill Summ*. 2016 Apr 1;65(No. SS-3):1-23.

Christensen DL, et al. Prevalence and characteristics of autism spectrum disorder among 4-year-old children – Early Autism and Developmental Disabilities Monitoring Network. *J Dev Behav Pediatr*. 2016 Jan;37(1):1-8.

Di Guiseppi CG, et al. Demographic profile of families and children in the Study to Explore Early Development (SEED): Case-control study of autism spectrum disorder. *Disabil Health J*. 2016 Jul;9(6):544-51.

Leeb RT, Fluke JD. Child maltreatment surveillance: enumeration, monitoring, evaluation and insight. *Health Promot Chronic Dis Prev Can*. 2015 Oct-Nov;35(8-9):138-40.

Schieve LA, et al. Population impact of preterm birth and low birthweight on developmental disabilities in US children. *Ann Epidemiol*. 2016;26(4):267-74.

Van Naarden Braun K, et al. Birth prevalence of cerebral palsy: A population-based study. *Pediatrics*. 2016;137(1):e20152872.

Visser SN, et al. (2015). Demographic differences among a national sample of US youth with behavioral disorders. *Clin Pediatr (Phila)*. 2016 Dec 23;55(14):1358-62.

Visser SN, et al. Vital signs: National and state-specific patterns of attention deficit/hyperactivity disorder treatment among insured children aged 2-5 years – United States, 2008-2014. *MMWR Morb Mortal Wkly Rep*. 2016 May 6;65(17):443-50.

### Spotlight On: Oklahoma State University

This Spotlight was contributed by Jane Silovsky PhD, University of Oklahoma Health Sciences Center and Amanda Sheffield Morris, Ph.D., IMH-E IV®, Oklahoma State University

Legacy for Children™ (*Legacy*) is an evidence-based parenting program—supported by NCBDDD in its development—that focuses on promoting children’s health and socio-emotional development through strengthening the parent-child relationship, supporting maternal confidence in parenting, and improving mothers’ social support.

It is a group-based program for mothers and their babies. The Tulsa community is implementing the *Legacy* UCLA curriculum, which begins prenatally and is offered through the first 3 years. In recognition of the need for culturally appropriate services, the *Legacy* program was translated and adapted for Spanish-speaking mothers and their infants. This program is being evaluated by University of Oklahoma Health Sciences Center and implemented through Oklahoma State University (OSU) in Tulsa.

Catholic Charities, one of the most respected resources in the Tulsa community for immigrant groups, helped OSU recruit Spanish-speaking mothers for the *Legacy* group. Furthermore, they provided a welcoming and comfortable space for the



Mothers in Oklahoma State University's Legacy for Children™ Spanish program in Tulsa, OK.

families to hold *Legacy* group sessions. The mothers in the Spanish groups were successfully engaged in the program. Initial findings from qualitative interviews suggest that mothers perceived the importance of both the social community that developed and the information that was gained.

Mothers in the Spanish *Legacy* groups particularly enjoyed the mother-only community-building session time (FUN Club). This mother-directed session component encourages mothers to socialize and build leadership and planning skills. The mothers were very creative during FUN Club, including coordinating a Zumba class and a facial tutorial from a make-up representative. They have also directly taught each other how to knit, make beaded bracelets, and other crafts. At the end of each FUN Club, Spanish groups have “convivios” which are very similar to a pot luck meal where the moms share homemade food with each other. Participants were all in agreement that they would recommend the *Legacy* program to Latino families, and it is a program OSU is particularly proud of.



## PROTECTING PEOPLE

### and Preventing Complications of Blood Disorders

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) is reducing the consequences of blood disorders by contributing to a better understanding of blood disorders and their complications.

Blood disorders affect millions of people in the United States. Patients with blood disorders live with the complications associated with their conditions, many of which are painful and potentially life threatening.

NCBDDD's Division of Blood Disorders (DBD) is committed to helping people with blood disorders. We contribute to a better understanding of blood disorders while working to develop, implement, and evaluate programs that help consumers and healthcare providers get critical information on preventing complications. We encourage action to improve the quality of life for people living with these conditions. With proper preventive actions and early medical intervention, many of these disorders and their complications could be eliminated.

### Accomplishments

- Launched Phase 2 of the Stop the Clot, Spread the Word Campaign, an important public health campaign to share information about blood clot risks and the signs and symptoms of blood clots. Phase 2 of the campaign targets patients recently hospitalized, those undergoing surgery, and victims of physical trauma. Campaign assets include web content, a video, an infographic, a radio news release, a mat release (an online feature article), a digital multimedia press release, and a Department of Health and Human Services (DHHS) blog.
- Recognized eight public and private healthcare practices and systems across the country as Healthcare-Associated Venous Thromboembolism (HA-VTE) Prevention Challenge Champions for their success in helping doctors prevent blood clots in their patients that occur as a result of hospitalization, surgery, or other healthcare treatment. CDC is sharing these best practices with others to help strengthen venous thromboembolism (VTE) prevention efforts.
- Performed inhibitor testing as part of the Community Counts Registry for Bleeding Disorders Surveillance, and provided the first ever estimates of the burden of inhibitors in the United States hemophilia population. An inhibitor is a potentially serious health problem



# PROTECTING PEOPLE

## and Preventing Complications of Blood Disorders

affecting people with bleeding disorders that stops or “inhibits” their treatment product from working, which makes it harder to stop or prevent a bleeding episode. Inhibitor testing strengthens prevention efforts by diagnosing inhibitors early, when they are more likely to be successfully eliminated using special treatment protocols.

- Worked with funded partners to implement the Community Counts project in hemophilia treatment centers (HTCs) across the United States, raising participation among all 136 federally-funded HTCs (as of July 31, 2016) to 100% for the HTC Population Profile, 92% for the Registry for Bleeding Disorders Surveillance, and 91% for Mortality Reporting.
- Supported and coordinated the development and promotion of a supplement issue of the American Journal of Preventive Medicine on sickle cell disease (SCD), entitled “Developing a Unified Approach for Sickle Cell Disease.” Articles in the supplement describe the state of sickle cell disease-related care in the United States. The articles highlight the public health impact of SCD on patients, healthcare providers and healthcare systems, and all the critical scientific work that is being done to reduce the burden of SCD on people living with the condition, as well as their families.

### Looking to the Future

NCBDDD’s (DBD) will continue to learn more about the factors that place people with hemophilia at risk for developing inhibitors. DBD will study and promote the use of periodic testing to find out if a person has an inhibitor, monitor complications from blood and treatment products, and research how well various treatment strategies prevent disease-related complications. We will focus on preventing blood clots that occur as a result of hospitalization, surgery, or other healthcare treatment. Also, we will work to improve laboratory techniques for inhibitor testing and for identifying factors that increase the risk for VTE. Lastly, DBD will focus on increasing healthcare provider and public knowledge and

awareness regarding signs and symptoms of blood clots. In addition, we will continue to emphasize the importance of early detection and diagnosis, and referrals to medical specialists and comprehensive care (an approach that uses the services of numerous professionals working together to provide for a patient’s needs, not just the medical and physical ones). DBD will continue research to understand complications of blood transfusions used to treat people with thalassemia and SCD.

### Notable 2016 Scientific Publications

Boylan B, et al. Survey of the anti-factor IX immunoglobulin profiles in patients with hemophilia B using a fluorescence-based immunoassay. *J Thromb Haemost.* 2016 Oct;14(10):1931-40.

Dargaud Y, et al. Achievements, challenges and unmet needs for haemophilia patients with inhibitors: Report from a symposium in Paris, France on 20 November 2014. *Haemophilia.* 2016 Jan;22(Suppl 1):1-24.

Dupervil B, et al. Correction: Emergency department visits and inpatient admissions associated with priapism among males with sickle cell disease in the United States, 2006–2010. *PloS One.* 2016 Aug 24;11(8):e0162056.

Mazepa M, et al. US Hemophilia Treatment Center Network. Men with severe hemophilia in the United States: Birth cohort analysis of a large national database. *Blood.* 2016 Jun 16;127(24):3073-81.

Pai M, et al. NHF-McMaster Guideline on Care Models for Haemophilia Management. *Haemophilia.* 2016 Jul;22(Suppl 3):6-16.

Paulukonis S, et al. Defining sickle cell disease mortality using a population-based surveillance system, 2004 through 2008. *Public Health Rep.* 2016 Mar-Apr;131(2):367-75.

Yeung CH, et al. Care models in the management of haemophilia: A systematic review. *Haemophilia.* 2016 Jul;22(Suppl 3):31-40.



## PROTECTING PEOPLE

### and Preventing Complications of Blood Disorders



**Spotlight On:**

## American Thrombosis and Hemostasis Network (ATHN)



**athn**<sup>™</sup>  
american thrombosis  
& hemostasis network



This Spotlight was contributed by Becky Dudley, Director of National Surveillance at ATHN.

The American Thrombosis and Hemostasis Network (ATHN) is a nonprofit organization dedicated to advancing and improving care for people with bleeding and clotting disorders. Founded in 2006, ATHN's mission provides stewardship of a secure national database (adherent to all privacy guidelines), which can be used to support clinical care and outcome analysis, research, advocacy, and public health surveillance. ATHN's ultimate goal is improving lives using standardized technology to secure data, advance knowledge, and transform care.

ATHN partners with the bleeding disorders community, government, and industry, and its ATHN Affiliates—the more than 135 hemophilia treatment centers (HTCs) across the United States that provide multi-disciplinary, comprehensive care to more than 32,500 patients annually. Through CDC's Community Counts Registry for Bleeding Disorders Surveillance, ATHN collaborates with CDC and HTCs to identify the number of people with bleeding and clotting disorders in the United States and monitor trends that will help prevent complications of these disorders. Together with the HTCs, ATHN is building the ATHNdataset—a safe, secure national dataset that has more than 30,000 patients who have opted to share their clinical and demographic data to support vital research.

ATHN provides funding for national data collection and research efforts on bleeding and clotting disorders. By leveraging its standardized integrated systems, data, and processes, ATHN helps decrease the time and cost for research and public health surveillance related to complications of bleeding disorders, such as inhibitors and hepatitis C, joint disease, venous thromboembolism (VTE), and cardiovascular and renal disease.

ATHN's many current projects include My Life, Our Future: Genotyping for Progress in Hemophilia; ATHN 2 – Factor Switching Study; ATHN 4 – Transition of Care for VTE Patients; ATHN 5 – Hepatitis C Treatment Outcomes; and quality initiatives led by the National Hemophilia Program Coordinating Center, which ATHN established in 2012 to identify gaps in services, standardize and increase access to care, and improve quality of care for those with bleeding disorders.

A multi-stakeholder Board of Directors representing ATHN Affiliates, regional leaders, and consumers govern ATHN. CDC, the Health Resources and Services Administration Maternal and Child Health Bureau, and the National Heart, Lung and Blood Institute provide input through liaisons to the Board and key committees. As committed stewards of the most current and extensive hemostasis and thrombosis data and analytic resources, and with results from future research and surveillance, ATHN promises to advance knowledge and transform care for patients with bleeding and clotting disorders.





# IMPROVING HEALTH

## of People with Disabilities

*CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) ensures that people with disabilities have the same opportunity for good health as people without disabilities.*

Disabilities may include difficulty with movement; hearing; seeing; or concentrating, remembering, or making decisions. One of every five adults in the United States has some type of disability, and many people will experience a disability during their lifetimes.

Compared to adults without disabilities, adults with disabilities are more likely to be obese, smoke, have high blood pressure, and be physically inactive. These are all preventable factors that can increase the risk for chronic diseases, such as heart disease, stroke, diabetes, and some cancers, which are also more common among adults with disabilities.

### Accomplishments

- Launched the Physical Developmental Delays: What to look for tool designed for parents who are concerned about the physical development of their child, but do not have a diagnosis. It was developed as part of a 3-year collaboration between NCBDDD and the American Academy of Pediatrics (AAP) in response to research generated from NCBDDD's Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet). The tool is an interactive checklist which gives parents the language and support they need to talk to their child's doctor about developmental concerns.
- Created Fragile X Myth Buster handouts for families and pediatricians to address misperceptions that can contribute to a delayed or missed diagnosis of fragile X syndrome (FXS). This project was developed as part of a collaboration with AAP to help pediatricians decrease the time between suspecting a developmental delay to getting the correct genetic test and diagnosis of FXS.
- Nineteen State Disability and Health Programs and two National Centers on Disabilities were awarded cooperative agreements to work to improve the health and quality of life among people with mobility limitations and/or intellectual disabilities through adaptation and implementation of evidence-based strategies in their communities, and at the state level. These 19 state programs ensure that individuals with disabilities are included in ongoing activities that prevent disease and promote health within the state. The National Centers on Disability—Special Olympics and the National





## IMPROVING HEALTH of People with Disabilities

Center on Health, Physical Activity and Disability (NCHPAD)—develop, implement, evaluate, and report on activities aimed at reducing health differences between people with and without disabilities and improving the health of people with mobility limitations and/or intellectual disabilities across their lifespans.

- Released Emergency Preparedness: Including People with Disabilities, an online catalog of materials developed by NCBDDD-funded disability and health programs to support emergency preparedness and response activities for people with disabilities. The catalog includes materials for identifying the needs of people with disabilities; communication and training; and assessment of emergency plans, shelters, and policies.
- Collaborated with the National Association of Chronic Disease Directors to fund communities within five of its State Disability and Health Programs (Iowa, Montana, New York, Ohio, and Oregon) to build disability inclusive communities. Provided technical assistance and guidance to NCHPAD, also funded by NCBDDD, for the development of their Inclusive Community Health Implementation Package (iCHIP), which was used to help the initiative. iCHIP is a set of resources and survey tools used to help communities gather and use information regarding healthy living resources for all members of the community, including persons with disabilities.

### Looking to the Future

NCBDDD collects data on people with genetic disorders, birth defects, and disabilities across the lifespan in order to promote

full participation for those affected. We strive to ensure that people with disabilities can fully participate in society. We will continue our research and public health programs, with an eye towards reducing health disparities and

Annual **healthcare costs** associated with disability are nearly



**\$400  
BILLION**

promoting inclusion for people with all types of disabilities, including those with intellectual disabilities. Health education and promotion is crucial to increase awareness. We will use all appropriate means to reach health professionals and other important audiences with information about disability and health.

### Notable 2016 Scientific Publications

Kwon JM, et al. Clinical follow-up for Duchenne muscular dystrophy newborn screening: A proposal. *Muscle Nerve*. 2016 Aug;54(2):186-91.

Lamb M, et al. Corticosteroid treatment and growth patterns in ambulatory males with Duchenne muscular dystrophy. *J Pediatr*. 2016 Jun;173:207-13.

Radcliff E, et al. Factors associated with the timeliness of postnatal surgical repair of spina bifida. *Childs Nerv Syst*. 2016 Aug;32(8):1479-87.

Reichard A, et al. Testing the feasibility of a passive and active case ascertainment system for multiple rare conditions simultaneously: The experience in three US states. *JMIR Public Health Surveill*. 2016 Aug 29;2(2):e151.

Routh JC, et al. Design and methodological considerations of the National Spina Bifida Patient Registry Urologic and Renal Protocol for the Newborn and Young Child. *J Urol*. 2016 Dec;196(6):1728-34.

Stevens AC, et al. Adults with one or more functional disabilities — United States, 2011–2014. *MMWR Morb Mortal Wkly Rep*. 2016;65:1021-25.

Valdez R, et al. Public health and rare diseases: Oxymoron no more. *Prev Chronic Dis*. 2016 Jan 14;13:e05.

Watson KB, et al. The attributable proportion of specific leisure-time physical activities to total leisure activity volume among US adults, National Health and Nutrition Examination Survey 1999–2006. *J Phys Act Health*. 2016 Aug;24:1-24.

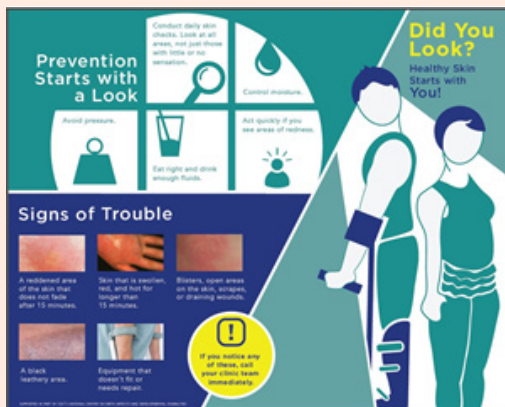
# IMPROVING HEALTH

## of People with Disabilities

### Spotlight On: Spina Bifida Association

This spotlight was contributed by Sara Struwe, MPA, President and CEO, Spina Bifida Association

Spina bifida (SB) is one of the most complex birth defects and leads to lifelong disability and potential illness. Identifying strategies to improve care and overall health are vital for the Spina Bifida Association (SBA).



Poster from the, "Did You Look?"  
Skin Breakdown Prevention Program.

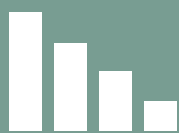
CDC awarded a cooperative agreement to SBA to bring together people and organizations that could implement a strategy to improve care and quality of life for people with SB. This ongoing collaboration is called the Spina Bifida Collaborative Care Network (SBCCN). This network takes research from CDC's National Spina Bifida Patient Registry and delivers those findings to healthcare professionals at SB specialty clinics.

The SBCCN will disseminate and implement a new project addressing pressure sores among people with SB. Almost half of all people with SB get pressure sores, and they are very difficult to treat. The National Spina Bifida Patient Registry data indicate this issue is an important part of SB care.

Practitioners from SB clinics reviewed existing literature on best skin care practices and determined that training and education reduced occurrences of pressure sores in hospitalized patients. These practices could likely be modified and used in an outpatient setting of a SB clinic. CDC and SBA created the *Did You Look?* skin breakdown prevention program. The program reinforces daily skin checks to prevent pressure sores and emphasizes the importance to quickly report and treat redness or suspicious changes to the skin. Program components include a risk assessment tool, a skin assessment tool, and an education campaign.

The SBA was able to use the partnership with CDC to leverage private dollars to fund the education component of the *Did you Look?* campaign. This project is the first organized effort to implement a targeted skin care program in SB clinics.

The SBCCN and the *Did You Look?* campaign are two examples of the partnership between CDC, the SBA, and SB specialty clinics to improve the health of people with SB.



# BUDGET

## FISCAL YEAR 2016 BUDGET

**CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD)** fiscal year (FY) 2016 appropriation includes \$135.610 million for Child Health and Development, Health and Development with Disabilities, and Public Health Approach to Blood Disorders.

Funds are currently supporting surveillance, research, and prevention activities that are addressing issues with the greatest public health burden and implementing strategies to improve health outcomes.

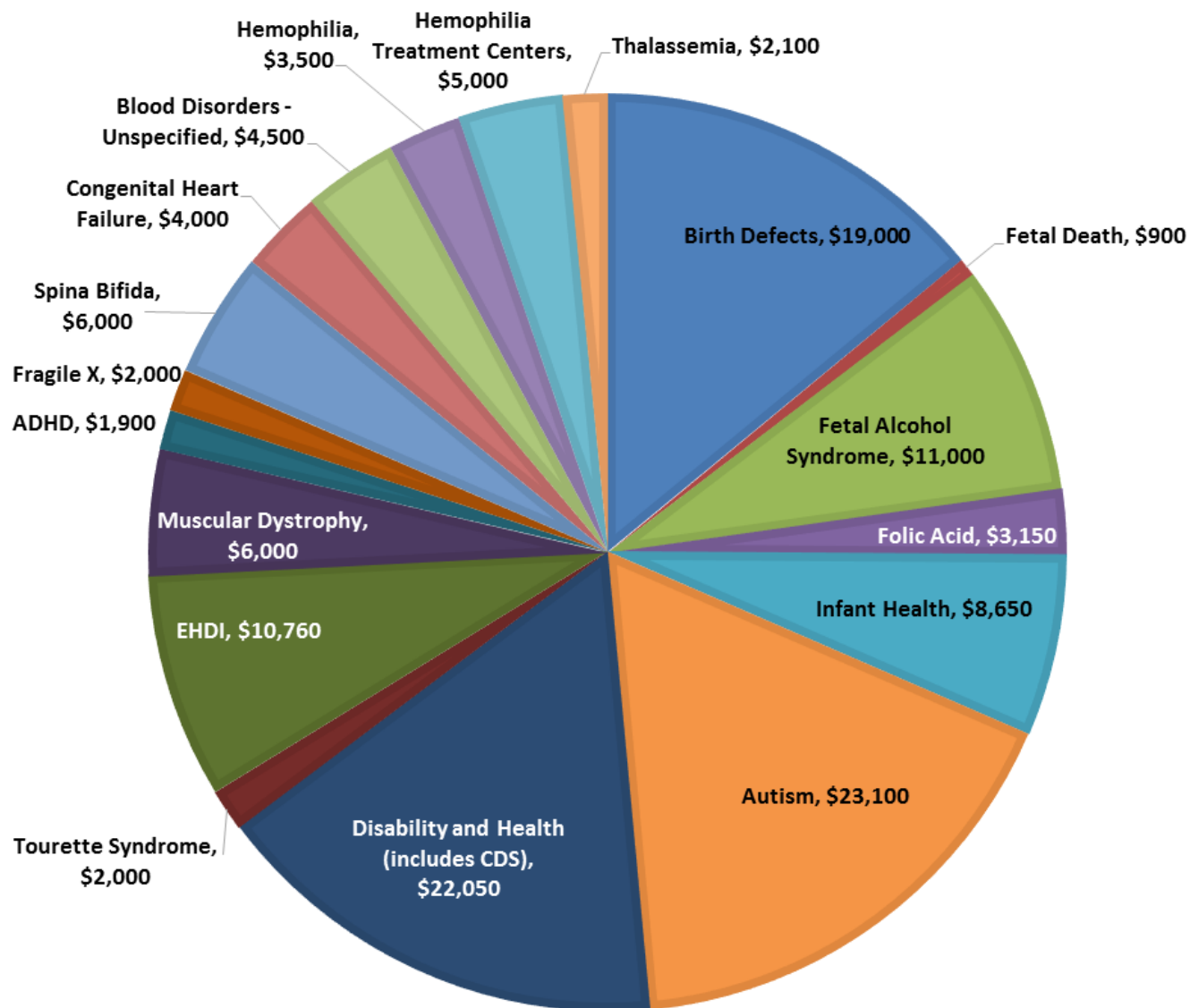
### NCBDDD FY 2016 Appropriations (in thousands)

Child Health and Development	\$65,800
Birth Defects	\$19,000
Fetal Death	\$900
Fetal Alcohol Syndrome	\$11,000
Folic Acid	\$3,150
Infant Health	\$8,650
Autism	\$23,100
Health and Development w/ Disabilities	\$54,710
Disability and Health (includes CDS)	\$22,050
Tourette Syndrome	\$2,000
EHDI	\$10,760
Muscular Dystrophy	\$6,000
ADHD	\$1,900
Fragile X	\$2,000
Spina Bifida	\$6,000
Congenital Heart Failure	\$4,000
Public Health Approach to Blood Disorders	\$15,100
Blood Disorders - Unspecified	\$4,500
Hemophilia	\$3,500
Hemophilia Treatment Centers	\$5,000
Thalassemia	\$2,100
NCBDDD Total	\$135,610



# BUDGET

## FISCAL YEAR 2016 BUDGET



ADHD: Attention-Deficit/Hyperactivity Disorder  
 CDS: Child Development Studies  
 EHDl: Early Hearing Detection and Intervention



## State Funding

### Select State-Based Activities and Funding

#### Alabama

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*

Alabama Department of Public Health (DD16-1604, 000793)  
**\$133,108**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*

Alabama State Department of Public Health (DD16-1603, 000017)  
**\$300,000**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*

University of Alabama (DD14-002, 001080)  
**\$66,943**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*

University of Alabama (DD14-002, 001079)  
**\$20,530**

*National Public Health Practice and Resource Centers on Health Promotion for People w/Disabilities*

University of Alabama, Birmingham (DD16-1602, 000022)  
**\$1,500,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*

Alabama Department of Health (DD16-1605, 000002)  
**\$399,903\***

*National Public Health Practice and Resource Centers on Health Promotion for People with Disabilities*

University of Alabama at Birmingham  
(DD12-1205, 000906) (DD15-1509, 000906)

**No Cost Extension ending 12/31/16**

*Improving the Health of People with Disabilities through State Based Public Health Programs*

Alabama Department of Public Health (DD15-1502, 000947)  
**Project ended 6/30/16**

## Alaska

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Alaska Department of Health (DD16-1604, 000780)  
**\$159,308**

*Fetal Alcohol Spectrum Disorders (FASD) Regional Training and Practice Centers*  
University of Alaska, Anchorage  
(DD14-1402, 001143)  
**\$275,000**

*Fetal Alcohol Spectrum Disorders Practice and Implementation Ctrs - High-Impact Projects for Practice*  
University of Alaska, Anchorage  
(DD14-1402 Suppl, 001143)  
**\$219,200**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
Alaska Department of Health  
(DD15-1502, 000948)  
**Project ended 6/30/16**

## Arkansas

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Arkansas Department of Health  
(DD16-1604, 000789)  
**\$138,241**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
University of Arkansas  
(DD16-1603, 000016)  
**\$400,000**

*Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)*  
Arkansas Children's Hospital Research Institute  
(DD13-003, 001039)  
**\$1,050,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
University of Arkansas (DD15-1501, 001163)  
**\$450,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and Other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
University of Arkansas  
(DD15-1501 Suppl, 001163)  
**\$37,500**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
University of Arkansas (DD15-1502, 000932)  
**Project ended 6/30/16**

## Arizona

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Arizona Department of Health Services  
(DD16-1601, 004950)  
**\$200,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
University of Arizona (DD15-1501, 001162)  
**\$549,939**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Developmental Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
University of Arizona (DD15-1501 Suppl, 001162)  
**\$62,500**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Arizona Department of Health Services  
(DD16-1605, 000020)  
**\$400,000\***

\* Zika funding



## STATE FUNDING

### Select State-Based Activities and Funding

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Arizona Department of Health Services  
(DD16-1604, 000826)  
**\$165,563**

### California

*Fetal Alcohol Spectrum Disorders (FASD) Regional Training and Practice Centers*  
University of California (DD14-1402, 001144)  
**\$275,000**

*Fetal Alcohol Spectrum Disorders Practice and Implementation Ctrs - High-Impact Projects for Practice*  
University of California (DD14-1402 Suppl, 001144)  
**\$151,200**

*Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) II*  
Kaiser Foundation Hospitals (DD11-002, 000748)  
**Did not fund in FY16; project ended 6/29/16**

*Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)*  
Stanford University (DD13-003, 001033)  
**\$800,000**

*Understanding the Complications Associated with Blood Disorders*  
Children's Hospital and Research Center at Oakland (DD14-1406, 001137)  
**\$100,000**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Children's Hospital of Los Angeles  
(DD14-002, 001068)  
**\$20,530**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Children's Hospital of Los Angeles  
(DD14-002, 001069)  
**\$66,875**

*OSTLTS Partnerships CBA of the Public Health System Change Lab Solutions (OT13-1302, 000328)*  
**\$135,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus-High Risk Local Areas*  
County of Los Angeles, Dept of Public Health  
(DD16-1606, 000142)  
**\$720,000\***

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
California Dept of Public Health (DD16-1605, 000040)  
**\$720,000\***

### Colorado

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Colorado Dept of Public Health and Environment  
(DD16-1601, 004940)  
**\$210,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
Colorado Dept of Public Health and Environment  
(DD15-1501, 001161)  
**\$550,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
Colorado Dept of Public Health and Environment  
(DD15-1501 Suppl, 001161)  
**\$62,500**

*Advanced Alcohol Screening & Brief Intervention (aSBI) & CHOICES in American Indian & Alaska Native Population thru Training & Technical Assistance*  
Denver Health and Hospital Authority  
(DD13-1301, 001046)  
**\$275,000**



*Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3*  
University of Colorado, Denver (DD16-001, 001210)  
**\$710,000**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Colorado Department Of Public Health And Environment (DD16-1604, 000822)  
**\$158,173**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders*  
Colorado State Department of Public Health and Environment (DD14-001, 001126)  
**\$465,000**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
University of Colorado, Denver (DD14-002, 001093)  
**\$67,082**

*Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes*  
University of Colorado, Denver (DD15-003, 001190)  
**\$99,984**

*Surveillance of Congenital Heart Defects across the Lifespan*  
University of Colorado (DD15-1506, 004935)  
**\$448,554**

*Location Based Smartphone Tech to Guide College Students Health Choices Phase II*  
Klein Buendel (PA14-071, 004995)  
**\$425,055**

## Connecticut

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Connecticut Department of Public Health (DD16-1604, 000817)  
**\$170,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Connecticut Department of Public Health (DD16-1605, 000010)  
**\$400,000\***

## Delaware

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Delaware Department of Health and Social Services (DD16-1604, 000819)  
**\$98,826**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
University of Delaware (DD15-1502, 000953)  
**Project ended 6/30/16**

## Florida

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Florida Department of Health (DD16-1601, 004946)  
**\$210,000**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Florida Department of Health (DD16-1604, 000810)  
**\$132,882**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
Florida Department of Health (DD16-1603, 000012)  
**\$300,000**

*Understanding the Complications Associated with Blood Disorders*  
University of Florida (DD14-1406, 001141)  
**\$99,987**

*\* Zika funding*



## STATE FUNDING

### Select State-Based Activities and Funding

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Florida Department of Health  
(DD16-1605, 000013)  
**\$720,000\***

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
Florida Department of Health  
(DD15-1502, 000992)  
**Project ended 6/30/16**

#### Georgia

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Georgia Department of Community Health  
(DD16-1604, 000824)  
**\$63,189**

*Surveillance of Congenital Heart Defects across the Lifespan*  
Emory University (DD15-1506, 004932)  
**\$475,000**

*OSTLTS Partnerships CBA of the Public Health System*  
Task Force for Global Health, Inc.  
(OT13-1302, 000216)  
**\$250,000**  
**\$100,000 \***

*Understanding the Complications Associated with Blood Disorders*  
Georgia State University Research Foundation  
(DD14-1406, 001138)  
**\$550,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Georgia Department of Public Health  
(DD16-1605, 000019)  
**\$560,000\***

*OSTLTS Partnerships CBA of the Public Health System*  
Association of State and Territorial Chronic Disease Program Directors (OT13-1302, 00225)  
**\$75,007**

*Strengthen Epi and Sustainable International PH Cap thru FETP*  
Task Force for Global Health, Inc.  
(GH15-1619, 001873),  
**\$154,964**

#### Hawaii

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
University of Hawaii as a bona fide for American Samoa (DD16-1604, 000777)  
**\$143,389**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
University of Hawaii as a bona fide for Marshall Islands (DD16-1604, 000796)  
**\$101,438**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
State of Hawaii Department of Health  
(DD16-1605, 000015)  
**\$400,000\***

#### Idaho

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Idaho Dept of Health and Welfare  
(DD16-1604, 000801)  
**\$148,337**

## Illinois

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Illinois Department of Public Health  
(DD16-1601, 004947)  
**\$210,000**

*Public Health Surveillance for the Prevention of Complications of Bleeding & Clotting Disorders*  
American Thrombosis and Hemostasis Network  
(DD15-1507, 000001)  
**\$4,300,000**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Illinois Department of Public Health  
(DD16-1604, 000825)  
**\$166,031**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus-High Risk Local Areas*  
City of Chicago Department of Public Health  
(DD16-1606, 000139)  
**\$200,000\***

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Illinois Department of Public Health  
(DD16-1605, 000006)  
**\$360,000\***

*OSTLTS Partnerships CBA of the Public Health System*  
American Academy of Pediatrics (AAP)  
(OT13-1302, 000167)  
**\$1,021,041**

*OSTLTS Partnerships CBA of the Public Health System*  
American Academy of Pediatrics (AAP)  
(OT13-1302, 000333)  
**\$125,000**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Lurie Children's Hospital of Chicago  
(DD14-002, 001091)  
**\$66,710**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Lurie Children's Hospital of Chicago  
(DD14-002, 001092)  
**\$20,530**

*Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes*  
Rush University Medical Center  
(DD15-003, 001186)  
**\$99,946**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
Illinois Department of Public Health  
(DD15-1502, 000938)  
**Project ended 6/30/16**

## Indiana

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Indiana State Department of Health  
(DD16-1604, 000790)  
**\$102,281**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Indiana State Department of Health  
(DD16-1605, 000030)  
**\$400,000\***

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Indiana University/Perdue University at Indianapolis (DD14-002, 001057)  
**\$66,440**

\* Zika funding



## STATE FUNDING

### Select State-Based Activities and Funding

#### Iowa

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Iowa Department of Public Health  
(DD16-1604, 000785)  
**\$174,200**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
Iowa Department of Public Health  
(DD16-1603, 000019)  
**\$300,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
University of Iowa (DD16-1605, 000005)  
**\$200,000\***

*Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)*  
University of Iowa (DD13-003, 001035)  
**\$800,000**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders*  
University of Iowa (DD14-001, 001119)  
**\$464,999**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders*  
University of Iowa (DD14-001, 001120)  
**\$250,000**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders*  
University of Iowa (DD14-001, 001118)  
**\$124,999**

*Utilizing Existing Birth Defects Surveillance Program to Include Surveillance Data on Stillbirths*  
Iowa Department of Public Health  
(DD10-1007, 000730)  
**No Cost Extension ending 9/29/16**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
Iowa Dept of Public Health (DD15-1502, 000949)  
**Project ended 6/30/16**

#### Kansas

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
University of Kansas Center for Research, Inc.  
(DD16-1603, 000006)  
**\$299,995**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Kansas Department of Health and Environment  
(DD16-1605, 000029)  
**\$400,000\***

#### Kentucky

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Kentucky Cabinet for Health and Family Services  
(DD16-1601, 004938)  
**\$210,000**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
Cabinet for Health Kentucky Family Services  
(DD16-1603, 000010)  
**\$150,000**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Kentucky Cabinet for Health and Family Services  
(DD16-1604, 000828)  
**\$163,719**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Kentucky Cabinet for Health and Family Services  
(DD16-1605, 000004)  
**\$400,000\***

## Louisiana

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Louisiana Office of Public Health  
(DD16-1604, 000841)  
**\$128,385**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Louisiana Office of Public Health  
(DD16-1605, 000026)  
**\$400,000\***

*Population Based Birth Defect Surveillance and Utilization of Surveillance Data by Public Health Program*  
Louisiana Department of Public Health (DD10-1001, 000623) (DD15-1508, 000623)  
**No Cost Extension ending 1/31/17**

## Maine

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs - Non-Research*  
Maine Department of Health (DD16-1604, 000813)  
**\$154,734**

## Maryland

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
Johns Hopkins University (DD15-1501, 001160)  
**\$450,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
Johns Hopkins University  
(DD15-1501 Suppl, 001160)  
**\$37,500**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
Maryland Department of Health Mental Hygiene  
(DD16-1603, 000005)  
**\$150,000**

*Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3*  
Johns Hopkins University (DD16-001, 001214)  
**\$1,009,813**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Maryland Department of Health and Mental Hygiene (DD16-1604, 000782)  
**\$125,453**

*National Public Health Practice and Resource Centers for Children with Attention-Deficit/Hyperactivity Disorder or Tourette Syndrome*  
CHADD, Inc. (Children & Adults with Attention Deficit Hyperactivity Disorder)  
(DD15-1505, 001049)  
**\$850,000**

*OSTLTS Partnerships CBA of the Public Health System*  
Association of University Centers on Disabilities (AUCD) (OT13-1302, 000140)  
**\$1,492,288**

*OSTLTS Partnerships CBA of the Public Health System*  
Association of University Centers on Disabilities (AUCD) (OT13-1302, 000324)  
**\$100,000**

*Evaluation of Health Promotion & Prevention Program for Blood Disorders*  
National Blood Clot Alliance  
(DD14-1405, 001153)  
**\$365,045**

*\* Zika funding*





## STATE FUNDING

### Select State-Based Activities and Funding

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Maryland Department of Health and Mental Hygiene (DD16-1605, 000033)  
**\$400,000\***

*Strengthening Public Health Laboratories*  
Association of Public Health Laboratories (OE15-1501, 000103)  
**\$50,000**

#### Massachusetts

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Massachusetts Department of Public Health (DD16-1604, 000783)  
**\$166,302**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
Massachusetts Department of Public Health (DD16-1603, 000002)  
**\$350,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Commonwealth of Massachusetts Department of Public Health (DD16-1605, 000011)  
**\$200,000\***

*Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)*  
Massachusetts Department of Public Health (DD13-003, 001037)  
**\$1,050,000**

*Public Health Research on Modifiable Risk Factors for Spina Bifida*  
Boston University Medical Campus (DD15-001, 001184)  
**\$310,000**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
Commonwealth of Massachusetts Department of Health (DD15-1502, 000940)  
**Project ended 6/30/16**

#### Michigan

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Michigan Department of Health and Human Services (DD16-1601, 004944)  
**\$210,000**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Michigan Department of Community Health (DD16-1604, 000798)  
**\$175,000**

*Data Coordinating Center for Autism and Other Developmental Disabilities Research and Epidemiologic Studies*  
Michigan State University (DD12-001, 000901)  
**Did not fund in FY16; project ended 5/31/16**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
Michigan Department of Health and Human Services (DD16-1603, 000001)  
**\$300,000**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
Michigan Department of Community Health (DD15-1502, 000930)  
**Project ended 6/30/16**

#### Minnesota

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Minnesota Department of Health (DD16-1601, 004939)  
**\$170,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
University of Minnesota (DD15-1501, 001171)  
**\$450,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
University of Minnesota  
(DD15-1501 Suppl, 001171)  
**\$37,500**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
Minnesota Department of Health  
(DD16-1603, 000009)  
**\$300,000**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Minnesota Department of Health  
(DD16-1604, 000842)  
**\$145,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Minnesota Department of Health  
(DD16-1605, 000007)  
**\$200,000\***

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Gillette Children's Specialty Healthcare  
(DD14-002, 001074)  
**\$67,090**

*Omnibus Solicited of the NIH, CDC, FDS, ACF for SBIR*  
Aster Labs (PA15-269, 002849)  
**\$187,045**

## Mississippi

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Mississippi Department of Health  
(DD16-1604, 000820)  
**\$102,345**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Mississippi State Department of Health  
(DD16-1605, 000035)  
**\$400,000\***

## Missouri

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
Washington University at St. Louis  
(DD15-1501, 001177)  
**\$550,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
Washington University at St. Louis  
(DD15-1501 Suppl, 001177)  
**\$62,500**

*Fetal Alcohol Spectrum Disorders (FASD) Regional Training and Practice Centers*  
University of Missouri  
(DD14-1402, 001145)  
**\$275,000**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
State of Missouri  
(DD16-1603, 000013)  
**\$150,000**

\* Zika funding



## STATE FUNDING

### Select State-Based Activities and Funding

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Missouri Department of Health and Senior Services (DD16-1604, 000815)  
**\$142,871**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
State of Missouri (DD16-1605, 000001)  
**\$400,000\***

*Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3*  
Washington University (DD16-001, 001216)  
**\$710,000**

### Montana

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Montana Department of Public Health and Human Services (DD16-1604, 000811)  
**\$153,713**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
Montana Department of Public Health (DD16-1603, 000018)  
**\$300,000**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
Montana Department of Public Health and Human Services (DD15-1502, 000991)  
**Project ended 6/30/16**

### Nebraska

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Nebraska Department of Health & Human Services (DD16-1604, 000797)  
**\$141,374**

### Nevada

*Fetal Alcohol Spectrum Disorders (FASD) Regional Training and Practice Centers*  
Board of Regents, University of Nevada Reno (DD14-1402, 001132)  
**\$343,000**

*Fetal Alcohol Spectrum Disorders Practice and Implementation Centers - High-Impact Projects for Practice*  
Board of Regents, University of Nevada Reno (DD14-1402 Suppl, 001132)  
**\$151,200**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Nevada Department of Health and Human Services (DD16-1604, 000788)  
**\$134,510**

### New Hampshire

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
New Hampshire Department of Health and Human Services (DD16-1604, 000827)  
**\$154,435**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
University of New Hampshire (DD16-1603, 000007)  
**\$400,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
New Hampshire Department of Health and Human Services (DD16-1605, 000009)  
**\$200,000\***

*Population Based Birth Defect Surveillance and Utilization of Surveillance Data by Public Health Program*

Trustees of Dartmouth (DD10-1001, 000607)  
(DD15-1508, 000607)

**No Cost Extension ending 5/31/16**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
University of New Hampshire (DD15-1502, 000954)  
**Project ended 6/30/16**

## New Jersey

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*

New Jersey Department of Health  
(DD16-1601, 004941)

**\$210,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*

Rutgers, The State University of New Jersey  
(DD15-1501, 001172)

**\$550,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*

Rutgers, The State University of New Jersey  
(DD15-1501 Suppl, 001172)

**\$62,500**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*

New Jersey Department of Health and Senior Services (DD16-1604, 000805)

**\$175,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*

New Jersey Department of Health  
(DD16-1605, 000008)

**\$560,000**

## New Mexico

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*

New Mexico Department Of Health  
(DD16-1604, 000807)

**\$59,678**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*

New Mexico Department of Health  
(DD16-1605, 000016)

**\$400,000\***

## New York

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*

Health Research Inc./New York State Department of Health (DD16-1604, 000795)

**\$113,029**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*

Health Research / NYSDOH (DD16-1603, 000004)

**\$350,000**

*Surveillance of Congenital Heart Defects Across the Lifespan*

New York State Department of Health  
(DD15-1506, 004931)

**\$422,096**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorder*

Center of Environmental Health / Health Research Inc./NYSDOH (DD14-001, 001054)

**\$100,000**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders*

Center of Environment Health/  
Health Research Inc./NYSDOH

(DD14-001, 001123)

**\$465,000**

*\* Zika funding*



## STATE FUNDING

### Select State-Based Activities and Funding

*Birth Defects Study To Evaluate Pregnancy exposures (BD-STEPS)*

Health Research Inc./NYSDOH-Center for Environmental Health

(DD13-003, 001032)

**\$800,000**

*National Public Health Practice and Resource Centers for Children with Attention-Deficit/Hyperactivity Disorder or Tourette Syndrome*

Tourette Syndrome Association, Inc

(DD15-1505, 001050)

**\$900,000**

*OSTLTS Partnerships CBA of the Public Health System*

March of Dimes Birth Defects Foundation

(OT13-1302, 000199)

**\$818,029**

*Evaluation of Health Promotion and Preventive Program for Blood Disorders*

Cooley's Anemia Foundation, Inc.

(DD14-1405, 001150)

**\$150,000**

*Evaluation of Health Promotion and Preventive Program for Blood Disorders*

National Hemophilia Foundation

(DD14-1405, 001154)

**\$593,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus-High Risk Local Areas*

New York City Department of Health

(DD16-1606, 000140)

**\$707,705\***

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*

Health Research, Inc. NYSDOH

(DD16-1605, 000021)

**\$720,000\***

*Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes*

New York State Psychiatric Institute

(DD15-003, 001188)

**\$199,004**

*Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes*

Institute for Basic Res in Developmental Disabilities

(DD15-003, 001189)

**\$349,861**

*Emerging Infections Program*

New York Department of Health

(CK12-1202)

**\$206,182**

*Surveillance of Congenital Heart Defects (CHDs) Adolescents /Adults*

Health Research Inc./NYSDOH

(DD12-1207, 001017)

**No Cost Extension ending 5/31/17**

*Improving the Health of People with Disabilities through State Based Public Health Programs*

Health Research Inc./NYSDOH

(DD15-1502, 000937)

**Project ended 6/30/16**

*Communication, Outreach, Collaboration and Prevention Activities to Support CDC's Response to Zika Virus*

March of Dimes

(OT13-1302, 000199)

**\$400,000 (\$325,000 from Zika Funds)**

### North Carolina

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*

University of North Carolina at Chapel Hill

(DD15-1501, 001175)

**\$550,000**



*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
University of North Carolina at Chapel Hill  
(DD15-1501 Suppl, 001175)  
**\$62,500**

*Surveillance of Congenital Heart Defects across the Lifespan*  
Duke University (DD15-1506, 004933)  
**\$404,350**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
North Carolina Department of Health and Human Services (DD16-1604, 000823)  
**\$153,376**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
North Carolina Department of Health and Human Services  
(DD16-1605, 000018)  
**\$560,000\***

*Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3*  
University of North Carolina, Chapel Hill  
(DD16-001, 001205)  
**\$960,000**

*Birth Defects Study To Evaluate Pregnancy exposureS (BD-STEPS)*  
University of North Carolina, Chapel Hill  
(DD13-003, 001036)  
**\$800,000**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorders*  
Research Triangle Institute  
(DD14-001, 001116)  
**\$425,000**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Duke University  
(DD14-002, 001082)  
**\$66,720**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Duke University  
(DD14-002, 001087)  
**\$20,530**

*National Public Health Practice and Resources Centers on Health Promotion for People with Disabilities*  
Duke University (DD11-1103, 000860)  
**No Cost Extension ending 9/29/16**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
North Carolina Department of Health and Human Services (DD15-1502, 000952)  
**Project ended 6/30/16**

## **North Dakota**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Minot State University – North Dakota  
(DD16-1604, 000802)  
**\$155,703**

*Improving the Health of People with Disabilities through State Based Public Health Programs*  
Minot State University – North Dakota  
(DD15-1502, 000950)  
**Project ended 6/30/16**

## **Ohio**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Ohio Department of Health  
(DD16-1604, 000804)  
**\$124,983**

*\* Zika funding*



## STATE FUNDING

### Select State-Based Activities and Funding

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs |*

Ohio State University  
(DD16-1603, 000015)  
**\$300,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*

Ohio Department of Health  
(DD16-1605, 000023)  
**\$560,000\***

*Using Longitudinal Data to Characterize the Natural History of Fragile X Syndrome to Improve Services and Outcomes*

Cincinnati Children's Hospital Medical Center  
(DD15-003, 001185)  
**\$99,998**

*Improving the Health of People with Disabilities through State Based Public Health Programs*

Ohio State University Foundation  
(DD15-1502, 000931)  
**Project ended 6/30/16**

### Oklahoma

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*

Oklahoma State Department of Health  
(DD16-1601, 004949)  
**\$210,000**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*

Oklahoma Department of Health  
(DD16-1604, 000814)  
**\$144,722**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*

Oklahoma Department of Health  
(DD16-1605, 000038)  
**\$324,667\***

### Oregon

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*

Oregon Department of Human Services  
(DD16-1604, 000799)  
**\$174,137**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*

Oregon Health and Science University  
(DD16-1603, 000014)  
**\$400,000**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*

Oregon Health and Science University  
(DD14-002, 001071)  
**\$67,099**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*

Oregon Health and Science University  
(DD14-002, 001058)  
**\$20,530**

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*

Oregon Health Authority  
(DD16-1601, 004951)  
**\$175,000**

*Improving the Health of People with Disabilities through State Based Public Health Programs*

Oregon Health and Science Center  
(DD15-1502, 000942)  
**Project ended 6/30/16**

### Pennsylvania

*Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships*

University of Pittsburgh  
(DD14-1403, 001135)  
**\$243,538**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus-High Risk Local Areas*

Philadelphia Department of Health  
(DD16-1606, 000138)  
**\$348,185\***

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*

Pennsylvania Department of Health  
(DD16-1605, 000031)  
**\$560,000\***

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*

University of Pittsburgh  
(DD14-002, 001078)  
**\$66,985**

## Rhode Island

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*

Rhode Island Department of Health  
(DD16-1601, 004943)  
**\$160,000**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*

Rhode Island Department of Health  
(DD16-1604, 000791)  
**\$168,289**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*

Rhode Island Department of Health  
(DD16-1605, 000003)  
**\$200,000\***

*Improving the Health of People with Disabilities through State Based Public Health Programs*

Rhode Island Department of Health  
(DD15-1502, 000944)  
**Project ended 6/30/1**

## South Carolina

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*

South Carolina Department of Health and Environmental Control (DD16-1604, 000779)  
**\$100,031**

*Coordinating Center for Research and Training to Promote the Health of People with Developmental and Other Disabilities*

University of South Carolina, Columbia  
(DD12-006, 001007)  
**\$3,016,367**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*

University of South Carolina (DD16-1603, 000011)  
**\$350,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*

South Carolina Department of Health and Environmental Control (DD16-1605, 000024)  
**\$400,000\***

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorder*

South Carolina Department of Health and Environmental Control (DD14-001, 001117)  
**\$465,000**

*Improving the Health of People with Disabilities through State Based Public Health Programs*

South Carolina Research Foundation  
(DD15-1502, 000945)  
**Project ended 6/30/16**

## South Dakota

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*

South Dakota Department of Health (DD16-1604, 000794)  
**\$135,943**

\* Zika funding





## STATE FUNDING

### Select State-Based Activities and Funding

#### Tennessee

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Tennessee Department of Health  
(DD16-1604, 000786)  
**\$163,742**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Tennessee Department of Health  
(DD16-1605, 000032)  
**\$400,000\***

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Vanderbilt University Medical Center  
(DD14-002, 001073)  
**\$67,188**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Vanderbilt University Medical Center  
(DD14-002, 001075)  
**\$20,530**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
Vanderbilt University Medical Center  
(DD15-1501, 001170)  
**\$450,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
Vanderbilt University Medical Center  
(DD15-1501 Suppl, 001170)  
**\$37,500**

*Emerging Infections Program*  
Tennessee  
(CK12-1202, 000198)  
**\$138,451**

#### Texas

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Texas State Department of Health Services  
(DD16-1601, 004942)  
**\$210,000**

*Fetal Alcohol Spectrum Disorders (FASD) Regional Training and Practice Centers*  
Baylor College of Medicine  
(DD14-1402, 001131)  
**\$342,960**

*Fetal Alcohol Spectrum Disorders Practice and Implementation Ctrs - High-Impact Projects for Practice*  
Baylor College of Medicine  
(DD14-1402 Suppl, 001131)  
**\$145,826**

*Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships*  
University of Texas, Austin (DD14-1403, 001147)  
**\$249,635**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Texas Department of State Health Services  
(DD16-1604, 000781)  
**\$116,498**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus-High Risk Local Areas*  
Houston Health Department  
(DD16-1606, 000141)  
**\$399,608\***

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Texas Department of Health Services  
(DD16-1605, 000036)  
**\$720,000\***

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Baylor College of Medicine  
(DD14-002, 001072)  
**\$66,776**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Baylor College of Medicine  
(DD14-002, 001070)  
**\$20,530**

*Public Health Research on Modifiable Risk Factors for Spina Bifida*  
University of Texas Health Science Center, Houston  
(DD15-001, 001179)  
**\$240,000**

## Utah

*Surveillance of Congenital Heart Defects Across the Lifespan*  
University of Utah  
(DD15-1506, 004934)  
**\$450,000**

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Utah Department of Health  
(DD16-1604, 000821)  
**\$116,954**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Utah Department of Health  
(DD16-1605, 000027)  
**\$200,000\***

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
IHC Health Services, Inc.  
(DD14-002, 001062)  
**\$66,766**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
IHC Health Services, Inc.  
(DD14-002, 001060)  
**\$20,530**

*Surveillance and Research of Muscular Dystrophies and Neuromuscular Disorder*  
University of Utah  
(DD14-001, 001108)  
**\$425,000**

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Utah Department of Health (DD16-1601, 004948)  
**\$210,000**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
Utah Department of Health  
(DD16-1603, 000003)  
**\$150,000**

## Vermont

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Vermont Department of Health  
(DD16-1604, 000818)  
**\$157,354**

*Improving the Health of People with Mobility Limitations and Intellectual Disabilities thru State-based Public Health Programs*  
Vermont Department of Health  
(DD16-1603, 000008)  
**\$150,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Vermont Department of Health  
(DD16-1605, 000034)  
**\$200,000**

\* Zika funding





## STATE FUNDING

### Select State-Based Activities and Funding

#### Virginia

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Virginia Department of Health  
(DD16-1604, 000812)  
**\$135,616**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Virginia Department of Health  
(DD16-1605, 000014)  
**\$560,000\***

#### Washington

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Washington Department of Health  
(DD16-1604, 000800)  
**\$174,044**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Seattle Children's Hospital  
(DD14-002, 001065)  
**\$66,429**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Seattle Children's Hospital  
(DD14-002, 001064)  
**\$20,530**

#### West Virginia

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
West Virginia Department of Health and Human Resources  
(DD16-1605, 000012)  
**\$384,300\***

#### Wisconsin

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Wisconsin Department of Health and Family Services  
(DD16-1604, 000806)  
**\$168,562**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Children's Hospital of Wisconsin  
(DD14-002, 001063)  
**\$67,060**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
Board of Regents, University of Wisconsin  
(DD15-1501, 001176)  
**\$550,000**

*Enhancing Public Health Surveillance of Autism Spectrum Disorders and other Disabilities through the Autism and Developmental Disabilities Monitoring (ADDM) Network*  
Board of Regents, University of Wisconsin  
(DD15-1501 Suppl, 001176)  
**\$62,500**

*Fetal Alcohol Spectrum Disorders (FASD) Regional Training and Practice Centers*  
Board of Regents of the University of Wisconsin System  
(DD14-1402, 001133)  
**\$273,739**

*Advanced Alcohol Screening & Brief Intervention (aSBI) & CHOICES in American Indian & Alaska Native Population thru Training & Technical Assistance*  
University of Wisconsin  
(DD13-1301, 001048)  
**\$275,000**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Wisconsin Department of Health Services  
(DD16-1605, 000025)  
**\$200,000\***

*Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE): Study to Explore Early Development (SEED) 3*  
University of Wisconsin, Madison  
(DD16-001, 001215)  
**\$710,000**

## Wyoming

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Wyoming Department of Health  
(DD16-1604, 000787)  
**\$141,948**

## District of Columbia

*National Public Health Practice and Resource Centers on Health Promotion for People w/ Disabilities*  
Special Olympics  
(DD16-1602, 000020)  
**\$4,500,000**

*Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships*  
American College of OB/GYN  
(DD14-1403, 001146)  
**\$250,000**

*Improving Fetal Alcohol Syndrome Disorder Prevention and Practice through National Partnerships*  
National Organization on Fetal Alcohol Syndrome Prevention  
(DD14-1403, 001148)  
**\$250,000**

*OSTLTS Partnerships CBA of the Public Health System*  
American Public Health Association (APHA)  
(OT13-1302, 000131)  
**\$13,747**

*Evaluation of Health Promotion & Prevention Program for Blood Disorders*  
Hemophilia Federation of America  
(DD14-1405, 001151)  
**\$550,000**

*CDC Collaboration with Academia to Strengthen Public Health Workforce Capacity*  
Association of Schools and Programs of Public Health  
(OE12-1201, 0002) University of Oklahoma  
**\$204,996**

*CDC Collaboration with Academia to Strengthen Public Health Workforce Capacity*  
Association of American Medical Colleges  
(OE12-1201, 00004) Duke University  
**\$205,000**

*CDC Collaboration with Academia to Strengthen Public Health Workforce Capacity*  
Association for Preventive Teaching and Research  
(OE12-1201, 0005)  
**\$25,298**

*Research Approaches to Improve the Care and Outcomes of People Living with Spina Bifida*  
Spina Bifida Association (DD14-002, 001077)  
**\$600,000**

*Improving the Health of People with Intellectual Disabilities*  
The ARC of the United States  
(DD12-1201, 000039)  
**Project Ended 3/31/16**

## Puerto Rico

*Population-Based Surveillance of Birth Defects and Data Utilization for Public Health Action*  
Puerto Rico Department of Health (DD16-1601, 004945)  
**\$170,000**

\* Zika funding



## STATE FUNDING

### Select State-Based Activities and Funding

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Puerto Rico Department of Health  
(DD16-1605, 000037)  
**\$400,000\***

#### Virgin Islands

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Virgin Islands Department of Health  
(DD16-1605, 000022)  
**\$399,770\***

#### Guam

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
University of Guam (DD16-1604, 000784)  
**\$147,658**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Guam Department of Public Health and Social Services (DD16-1605, 000028)  
**\$326,680\***

#### American Samoa

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
American Samoa Department of Health  
(DD16-1605, 000039)  
**\$400,000\***

#### Commonwealth of the Northern Mariana Islands

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Commonwealth of the Northern Mariana Islands  
(DD16-1604, 000792)  
**\$68,860**

*Surveillance, Intervention, and Referral to Services Activities for Infants with Microcephaly or Other Adverse Outcomes linked with the Zika Virus*  
Commonwealth Health Corporation, Northern Mariana Islands (DD16-1605, 000017)  
**\$400,000\***

#### Palau

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Republic of Palau Ministry of Health  
(DD16-1604, 000809)  
**\$93,496**

#### Federated States of Micronesia (FSM)

*Development, Maintenance and Enhancement of Early Hearing Detection and Intervention Information System (EHDI-IS) Surveillance Programs*  
Federated States of Micronesia Department of Health, Education and Social Affairs  
(DD16-1604, 000778)  
**\$91,540**

#### China

*Conducting Public Research in China*  
Chinese Center for Disease Control and Prevention (GH12-005, 000636)  
**\$50,000**

#### Switzerland

*Global Non-Communicable Disease Prevention and Promotion of Health*  
World Health Organization (GH14-1420, 001235)  
**\$837,291**

\* Zika funding

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